

May 19, 2021

Dear Chair Bronna Kahle, Vice Chair Meerman, and members of the committee:

I am writing to urge the committee to strengthen and pass HB 4762, which would make it illegal under Michigan law to deny a person an organ transplant (or related medical procedure) solely on the basis of the individual's disability. At least 20 other states — including Ohio and Indiana — have enacted similar laws.<sup>1</sup>

My eight-year-old nephew Max has Down Syndrome and lives in Grosse Pointe Woods, Michigan. It is incomprehensible that — should he ever need an organ transplant — he might be denied that life-saving gift due to his disability. But surveys of medical professionals and people with disabilities, and the experience of people with Down Syndrome, autism, and other disabilities shows that this is the grim reality.



I have been on the organ donor list since I got my first driver's license in Michigan at age 16. It is equally outrageous that discrimination could prevent my organs from being transplanted into a disabled person who is a match and would otherwise be next in line.

Yet a 2008 survey by Stanford found 85% of surveyed pediatric transplant centers sometimes consider intellectual or developmental disability as a factor in determinations of transplant eligibility.<sup>2</sup> A survey also found 71% of heart programs always or usually use intellectual or developmental disability in transplant eligibility.

Here are two examples of people with disabilities who faced this potentially fatal discrimination:

- Ellie Ward was denied a heart transplant in Ohio in 2018 because she has Down Syndrome. She was three years old.<sup>3</sup>
- Amelia Rivera was denied a transplant from a living donor, her mother, at a New Jersey Children's Hospital because of her Wolf-Hirschhorn syndrome, which causes intellectual disability. (The family rallied public support and

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<sup>1</sup> See: <https://www.ndss.org/programs/ndss-legislative-agenda/healthcare-research/nondiscrimination-in-organ-transplantation-laws-toolkit/> for the list and other information.

<sup>2</sup> Richards CT, Crawley La Vera M, Magnus D (2009). Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 13:843–850.

<sup>3</sup> <https://dayton247now.com/news/local/lawmakers-push-for-change-after-3-year-old-denied-heart-transplant-due-to-down-syndrome>

the kidney was successfully transplanted after the hospital reversed course due to public outcry.<sup>4</sup>)

Discrimination against people with disabilities in organ transplants is not legal under federal law, but it is widespread. The reason state laws are also needed include to provide for more rapid and effective enforcement, to increase awareness that this type of discrimination is illegal and wrong, and to send the message to people with disabilities that their state values their lives and will work to end discrimination against them.

While I am very grateful for HB 4762, I have noticed that some of the other laws on this issue included provisions that I encourage the committee to incorporate to provide more comprehensive protections:

**1. Providing More Comprehensive Protection Related to Discrimination Based on Perceived Ability to Comply With Recovery Plans**

Some of the discrimination against people with intellectual disabilities in organ transplants has been rooted in assumptions that they would not comply with a post-operation requirement, such as medication adherence, while ignoring these individuals' support systems. I am concerned that, as drafted, HB 4762 may not prevent discrimination in these cases, as opinions about post-operation adherence may not be considered to be "solely" based on the person's disability. More comprehensive language would help ensure that any such evaluation also consider their support system.

For example, it could provide:<sup>5</sup>

- (a) If an individual has the necessary support system to assist the individual in complying with post-transplantation medical requirements, a covered entity may not consider the individual's inability to independently comply with the post-transplantation medical requirements when evaluating the individual for an organ transplant or related procedures.
- (b) A covered entity shall make reasonable modifications in policies, practices or procedures, when the modifications are necessary to allow an individual with a disability access to services, including transplantation-related counseling, information, coverage or treatment, unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the services.

["Covered entity" would need to be defined and can be drawn from Kan. Stat. Ann. § 65-3276.]

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<sup>4</sup> See: Kim Painter, "Disabled N.J. girl thrives, inspires after transplant," USA Today, Oct. 5, 2013.

<sup>5</sup>This language is similar to, but not identical to other laws including Maryland and Kansas'. See: Kan. Stat. Ann. § 65-3276.

## 2. Providing for Relief and Enforcement

Discrimination in organ transplants is already illegal under federal law, but surveys show it remains widespread. Adding language to provide for expedited relief and including attorneys' fees can help ensure this bill truly has teeth — and that disabled patients get relief before it is too late. The Attorney General should also be authorized to bring cases and to monitor compliance. Here is possible language:

[new section]

(1) Any individual who has been subjected to discrimination in violation of this part may initiate a civil action in a court of competent jurisdiction. In a civil action commenced under this subsection, the court may:

(a) Grant injunctive, temporary, preliminary or permanent relief;

(b) Require an auxiliary aid or service or the modification of a policy, practice or procedure or require an alternative method;

(c) Require that facilities shall be made readily accessible to and usable by individuals with disabilities;

(d) Grant such other relief as the court considers appropriate, including monetary damages; and

(e) Allow for the recovery the cost of the suit including reasonable attorneys' fees to aggrieved persons.

(2) The court must accord priority on its calendar and expeditiously proceed with an action brought under this part.

(3) Nothing in this section is intended to limit or replace available remedies under the Americans with Disabilities Act of 1990 and the Americans with Disabilities Amendments Act of 2008 or any other applicable law.

[new section]<sup>6</sup>

(1) The attorney general shall investigate alleged violations of this section and shall undertake periodic reviews of compliance of covered entities.

(2)(a) If the attorney general has reasonable cause to believe that a person or group of persons is engaged in a pattern or practice of discrimination under this section or a person or group of persons has been discriminated against under this section and such discrimination raises an issue of general public importance, the attorney general may commence a civil action in an appropriate state court.

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<sup>6</sup> This section is similar to, but provides more damages than, a provision in Massachusetts' law. M.G.L.A. 111 § 236 (\$50,000 is vastly inadequate for discriminating against individuals with disabilities in transplants.)

(b) The court may assess a civil penalty against a covered entity of not more than \$500,000 for a first violation and not more than \$1,000,000 for a second or subsequent violation.

Thank you for your attention to this important issue, and for considering my input.

Warm regards,

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